

heartnotes™

(A JOURNAL OF HOSPICE & PALLIATIVE CARE)



Advanced Illness

EDUCATION, TOOLS AND
SUPPORT FOR LONG-TERM
CONDITIONS



**Your
Five
Wishes**

(See page 12)

If you'd like to join the *Heartnotes* mailing list and receive each issue, please visit www.EvercareHospice.com/Subscribe to register for your free subscription.

Hospice Facts
and Figures

Avoiding
Caregiver Burnout

editor's note

There are very few taboo subjects left in our culture. We openly discuss our finances and our relationships. We share our lives through website postings and text messages. But even with all these candid exchanges, one topic can still chill the conversation: Death, dying, and what we would each want at the end-of-life.



National Healthcare Decisions Day, held on April 16, is a reminder that we should all make our end-of-life wishes clear to our families and health care providers. It's part of a grassroots effort to promote advance care planning and informed decision making. It's a time to define our choices and take steps to ensure that those choices are known and protected.

End-of-life choices are deeply personal and individual, and sometimes not what you'd expect. That's why it's essential that we document what we would want and wouldn't want, instead of assuming that our loved ones and doctors know what to do on our behalf.

These choices are broader than medical decisions. End-of-life planning should include all aspects of care, including your personal, emotional, social and spiritual needs. It should identify which person you want to make decisions for you if you can't make them yourself. It should express what types of surroundings and people would make you most comfortable as you approach death.

One of the most useful advanced planning tools available is Five Wishes. It's known as the "living will with a heart and soul" because it helps you to speak openly and honestly about your beliefs. Five Wishes was written with the help of the American Bar Association and has been deemed a valid, stand-alone living will by 42 states. It is available in 23 different languages, plus American English Braille, and is easy to use.

Your death experience should reflect what you value in life. Creating a living will and documenting your expectations for care is one of the greatest gifts you can give yourself and the people around you. Don't wait another day to share your choices and make your end-of-life wishes known. 🌈

Sincerely yours,
Jennifer Gatti
Jennifer Gatti

i Want to learn more about Five Wishes and how to order your copy? Turn to pages 12-13 of this issue of *Heartnotes*.

ABOUT HOSPICE

Hospice is a patient-centered, interdisciplinary approach to end-of-life care that respects the needs of terminally ill patients and helps them remain as comfortable as possible, with loved ones nearby. At the center of hospice care is the belief that every person has the right to die pain-free and with dignity, and that families will receive the necessary support to allow patients to do so.

ABOUT PALLIATIVE CARE

Palliative care is for those who have advanced illness but are continuing curative therapies. Care includes physician consultation and support services for the patient and family. This can be a time to learn about how an illness is likely to progress and plan for end-of-life care.

Heartnotes is published by Evercare[™] Hospice and Palliative Care, 9701 Data Park Drive, Minnetonka, MN 55343. We provide compassionate care for those facing end-of-life issues and personal support to their families. We are proud to offer resources, education and advocacy on issues relating to long-term care, hospice and palliative care, and the needs of patients and caregivers. This information is not intended as medical advice. If you are concerned about your health or any symptoms you may be experiencing, please contact your primary care provider.

To learn more about Evercare[™] Hospice and Palliative Care and the services we provide, please call 1-877-765-3917 or visit us online at www.EvercareHospice.com.

Evercare[™] Hospice and Palliative Care is offered by Evercare Hospice, Inc. Evercare Hospice and Palliative Care is committed to the policy that all persons shall have equal access to its programs, facilities, and employment without regard to race, sex, religion, color, age, national origin, disability, sexual orientation or other protected factor.

* contents



4 {Advanced Illness}



7 {Focus on Caregivers}



14 {Fulfilling Dreams}

4 **Advanced Illness:**
Extending the continuum of care.

7 **Focus on Caregivers:**
Understanding and avoiding burnout.

10 **Voices of Care:**
In their own words.

12 **Five Wishes:**
Protecting your dignity at the end-of-life.

14 **Fulfilling Dreams:**
Comfort, closure and celebration.

17 **Hospice in America:**
2008 facts and figures.

19 **Resources:**
Websites and information for you.



ADVANCED ILLNESS: EXTENDING THE CONTINUUM OF CARE

IT'S HUMAN NATURE TO RESIST BAD news. We wish for the best and avoid thinking about the worst. When faced with a life-limiting illness or serious diagnosis, it's normal for patients and their families to hope it will all just go away.

Of course, wanting better news won't make it so. But, through Advanced Illness programs, patients and families can receive tools, support, care and education that help them manage their condition, plan for the future and maximize their quality of life.

Advanced Illness programs take a comprehensive approach to care for people with chronic, irreversible disease who have a life expectancy of 12 to 24 months. It's a compassionate, evidence-based way of improving peace of mind, managing symptoms and empowering members and families.

These programs incorporate palliative principles and curative therapies. Specifically, Advanced Illness programs are designed to:

- » Emphasize open, honest communication about a patient's current condition and the likely progression of their disease.
- » Align the course of treatment and plan of care with the patient's values and goals.
- » Minimize physical, psychological and spiritual distress.

- » Support family members and caregivers.
- » Empower patients to become more active participants in medical care they receive as life prolonging interventions become less effective.
- » Neither hasten nor prolong death.
- » Provide necessary medical resources in the least intensive setting.

By introducing Advanced Illness services early, patients and families can make informed decisions about their care today while preparing for the future. It allows patients to live more fully by reducing the fear of the unknown. And, it applies sophisticated pain and symptom management techniques to support a patient's independence and overall well being. Ultimately, Advanced Illness programs help ensure that patients receive the right care at the right time, in the manner that is most appropriate and meaningful for them.

CREATING AN ADVANCED ILLNESS PLAN

Because patients and families often lack clarity about the progression of illness, they sometimes put off the important conversations about a patient's end-of-life

wishes. This misunderstanding is a major driver of avoidable admissions and unnecessary suffering. By participating in an Advanced Illness program, patients and families gain greater trust, lessen their uncertainty, reduce confusion and conflict, and strengthen their peace of mind.

Advanced Illness care plans reflect and honor a patient's individual preferences and beliefs. There is no "correct" answer about what a patient "should" want. Each care plan focuses on what each person needs today and their expectations for the future.

Often, patients have one of three major goals for their advanced illness care plan:

- » **Longevity**, or the desire to extend life above all else. For these patients, length of life is paramount. Extending life has greater value than any amount of suffering that may be necessary for treatment.
- » **Function**, by slowing their decline in condition. These patients value length of life but may limit aggressive treatment. For them, function and independence may become more valued than longevity.

- » **Comfort**, controlling pain and limiting medical interventions. These patients want maximum relief and comfort. The quality of their remaining time is more important to them than the quantity.

In creating an Advanced Illness plan, you may find that you are drawn to one of these goals exclusively, or that there are elements of each that speak to you. Working with your doctor and other providers, you can create a care plan that reflects your wishes and that is adaptable as your needs change.

Patients participating in Advanced Illness programs often work with a care coordinator. Coordinators are typically Registered Nurses or Nurse Practitioners. They work with patients and their families, caregivers and providers to fulfill the goals of a patient's care plan. These coordinators act as a vital communications link and serve as trusted guides to navigate the health care system. They anticipate, identify and resolve health issues and related needs before they become crises and help patients get the care they need and deserve. ❖

Advanced Illness programs take a comprehensive approach to care for people with chronic, irreversible disease.

* Patient and Family Stories

Richard H.

Nine years ago, 60 year old Richard H. was scuba diving and rock climbing. Four years ago, he was diagnosed with multiple sclerosis and began a struggle with chronic pain. Although Richard moved to a handicapped-accessible apartment that allowed him to live independently, his daily needs were not being met adequately.

Working with an advanced illness care coordinator, Richard received much needed pain medications, adaptive equipment and the help of a home health aide three times a week. He was relieved to know that he can be comfortable and have assistance with his daily needs while living in his own home.

Roxanne S.

Roxanne S. first learned about Advanced Illness programs while helping her father, Albert,

examine options for his care. Albert had several serious health issues and was receiving hospice services, but was considering leaving hospice to explore a pain management procedure that was considered an aggressive treatment.

In late April 2009, Albert transitioned from hospice to an Advanced Illness program. His care coordinator, Mary, met with Albert and Roxanne to complete an assessment and provide support and education. "It gave my Dad peace of mind to know that Mary was coming and would help us sort things out," says Roxanne.

Albert decided to return to hospice in July and passed away at home the next month in the arms of his daughter. Roxanne was appreciative of Mary's care and support. "When you are caring for someone who is terminally ill, it means so much to have someone who can come to the house to provide support," she says.

* What Quality of Life Means to YOU

The term "quality of life" is often used at a time when patients, families and health care professionals are trying to understand the impact of a serious illness. It is multi-dimensional and includes physical, social, psychological and spiritual considerations. It is completely personal and can only truly be determined by the patient.

A quality of life assessment should be a review from the patient's point of view. Consider these questions when describing your overall quality of life. The sum of your answers will give you and your doctor a snapshot of your world and how you see it today. This snapshot helps everyone understand what is important to you at this time.

Physical Function

- » Are you experiencing pain or other distressing symptoms?
- » How does your illness impact your daily activities?

Social Interactions

- » How are you getting along with family and friends as a result of your illness?

- » Are there things you enjoy doing that your illness is interfering with?

Psychological Well-Being

- » Have you been feeling worried or sad about your illness?
- » How are you coping with your illness?

Spiritual or Existential Concerns

- » How have your religious beliefs been affected by your illness?
- » Do you find yourself wondering what is the meaning of all this?

Identifying the elements of your illness that reduce your quality of life helps to focus your care and treatment. Your goals and wishes also become clear, which is crucial for making important decisions.

Source: Chang, V. and Weissman, D. *Fast Facts and Concepts #51 Quality of Life, September 2006. End-of-Life Physician Education Resource Center www.eperc.mcw.edu.*



FOCUS ON CAREGIVERS:

UNDERSTANDING AND AVOIDING BURNOUT

CARING FOR A LOVED ONE CAN provide emotional rewards, but it can also take a toll, forcing you to make compromises and sacrifices. It's easy to become so focused on a vulnerable family member or friend that you lose track of the fact that you too, have needs. It's called caregiver fatigue, or burnout — and it can affect both your quality of life and your ability to provide effective care for your loved one.

Some of the signs of caregiver burnout include:

- » **Irritability.** You snap at people for small things and lose patience easily.
- » **Withdrawal.** You don't stay in touch with friends or pursue activities that you enjoyed in the past.
- » **Fatigue.** You are constantly tired and exhausted.
- » **Insomnia.** You have a hard time getting to sleep or staying asleep, or you sleep restlessly.
- » **Apathy.** You feel numb and must force yourself to do routine caregiver tasks.
- » **Appetite Changes.** You eat more than you used to, or don't feel like eating anything.

» **Increased Substance Use.** The only relief you can get is from alcohol, drugs or smoking.

» **Guilt.** You think you are not doing enough, or you feel resentment over the amount of work you are doing.

» **Anxiety.** You constantly wonder if you are making the best and right decisions for your loved one. You may also feel stress about conflicting ideas about the best care for your loved one.

To care for someone else, you must take care of yourself first. You may be less vulnerable than the person you are caring for, but you're no less important. As you take care of the one you love, make sure you take care of yourself as well.

Here are some ways to avoid caregiver burnout:

- » **Exercise.** Even if you do not have time for a formal workout, incorporate exercise into your daily routine. For example, take a walk around the doctor's office or hospital grounds during your loved one's appointment.
- » **Eat properly.** Many times caregivers are so absorbed in preparing meals for their loved ones they neglect their own nutritional needs.

* Want to Learn More?

If you think an Advanced Illness program could be right for you or a loved one, or would like to learn more, contact any of the Evercare Hospice locations listed on page 16. You can also call Evercare Hospice 24 hours a day at 1-877-273-5534 or visit us online at www.EvercareHospice.com. Our staff can discuss your needs and assist you with a referral to an Advanced Illness program.

It's easy for caregivers to lose track of the fact that they too, have needs.

focus on caregivers

- » **Keep your doctor appointments.** Most caregivers ignore their own health needs. But if you get sick, who will care for your loved one?
- » **Keep a journal or diary.** By recording what you are going through and how you are feeling, you can better evaluate whether things are improving or worsening over time, and identify what other support you might need.
- » **Pursue hobbies.** Don't lose touch with the things that give you pleasure. Continue to do what brings you joy, even if it is less frequent than before.
- » **Blow off steam.** Go to the movies, go to dinner, have fun, see friends, play games. It's okay to escape and not focus all your energy on your loved one's illness.
- » **Accept the help others offer.** Trust in their willingness to help. Suggest specific things they can do.
- » **Tap into your support network.** Many people want to help, but don't know what to offer. Ask friends, relatives, neighbors, co-workers and people in your faith community to help you with tasks they feel best doing.
- » **Join a caregiver's support group.** There are many community resources that can offer you extra help and time away.
- » **Get professional help.** Care services can be provided in the home, in an adult day center or in a nursing home or assisted living facility.

BRIDGING THE GAP: LONG-DISTANCE CAREGIVING

Physical distance can further complicate the responsibilities of caregiving. About 7 million adults in the U.S. are caregivers for family members who live an hour or more

away. Since you can't often be there in person, this type of caregiving brings its own set of challenges. Here are some tips for long-distance caregivers.

Get informed. Learn as much as you can about your loved one's condition, including their medical, physical, financial, social, emotional and safety needs. This information can help you anticipate potential issues and prevent a crisis.

Collect contact info. Create a notebook or folder with all the vital information about your loved one's health care, social services, contact numbers, financial accounts, etc. Ask your loved one about giving you written permission to receive medical and financial information.

Find trusted "eyes and ears." Seek help from people in the immediate community: a next door neighbor, a friend, a doctor. Ask them to check in on your loved one and to be your eyes and ears. Encourage them to call if they see anything that concerns them.

Make a medication list. Include all prescriptions, over-the-counter medications, vitamins and supplements. Get doses and



schedules. Update it regularly and keep a copy with you.

Talk about the future. Find out if your loved one has an advance directive with health care preferences, and if not, encourage them to document their wishes. Make sure you have a copy and you know where a copy is kept.

Evercare™ Solutions for Caregivers can be an important link between you and your aging loved ones. Their Caregiver Coaches have the information, resources and expertise to support you and develop a customized care plan. For a free consultation, call 1-877-765-4473 or visit them online at www.EvercareHealthPlans.com/Caregiver.

Get in touch and stay in touch. Schedule regular calls with doctors and other caregivers to get up-to-date information about your loved one's health and condition. Consider conference calls, so other relatives can participate in one conversation. 🗨️

About 7 million adults in the U.S. are caregivers for family members who live an hour or more away.

✿ A Caregiver Testimonial: Carolyn M.

My Uncle Nick was diagnosed with non-Hodgkin's Lymphoma. Two of Nick's sons took responsibility for his care, helping him to appointments, keeping track of his medications and coordinating with different doctors. But, even though he didn't want to admit it, Nick was suffering. His health was declining, and he had become too weak to walk.

I called Evercare Solutions for Caregivers to learn about their services. Our Evercare coordinator, Kathy, soon sent a nurse to Nick's home to evaluate his condition and his living situation. The nurse's evaluation and Kathy's consultation with our family helped everyone acknowledge Nick's chronic pain and understand that there were resources available to help him.

We took Kathy's advice. Within two weeks, Nick had new medications, occupational therapy to conserve energy,

physical therapy to help with his aches and ease his breathing and handle bars for the shower. Kathy explained that, while palliative care or hospice might not be appropriate yet, we needed to prepare ourselves for the time when they would be.

The result was remarkable, both in terms of Nick's quality of life and his readiness to accept help. My parents and other cousins felt more empowered to help out; they began rotating meal duty and reorganized Nick's home to make his daily activities less strenuous.

Recently, my cousin called to say that Nick will be transitioning to Evercare Hospice. Nick will live his last days with the dignity that his life has come to symbolize. Evercare Solutions for Caregivers and Kathy's advice, both pragmatic and sensitive, have made this all possible.



Chaplain
Anne Chida

VOICES OF CARE: IN THEIR OWN WORDS

OUR DEDICATED CARE TEAMS are the heart of Evercare Hospice. In their own words, here are just a few examples of what brought these professionals to hospice, and why they remain so dedicated to the patients and families they serve.

Beth Martin, LPN, CHPLN

Hospice is not just a philosophy or service for me, it is a way of life. When I started with hospice, I immediately began to realize the large difference we make in people's lives.

One of my most rewarding hospice experiences happened when I received a call that a patient of mine was close to the end. Her two sons were at bedside, and I sat with them for the next several hours. The facility where my patient lived was having difficulty getting the patient comfortable, and the nursing staff was looking for medication recommendations. I was able to make recommendations to ensure the patient was comfortable in her last hours.

As it was to be her birthday the next day, the sons wanted to thank her and share a happy birthday toast with her at midnight. At midnight, the sons poured "glasses" of champagne (in coffee cups) and thanked their mother for her wonderful life. They reminisced about all the good times they had had together. We sat together and one of the sons said a prayer. About 15 minutes later, the patient passed comfortably. The sons, although sad, were glad that their mother had

passed on comfortably and thanked me for the help. It was a very special moment in my career.

To me, what makes a good hospice is a good team. If you need help from the other disciplines, it is imperative that everyone be responsive. Many times when we arrive at a patient's bedside, it is clear that they need more than nursing services at that time. I deeply appreciate the collaboration that I have with the chaplains, social workers, hospice aides and also the office staff that keep us all connected. It is amazing to be part of a team that works together for the benefit of the patient.

On a personal note, I was diagnosed with breast cancer in May 2007. I went through surgery, chemotherapy and radiation. During the six months that I was on sick leave, not one week went by that I did not receive a card from my co-workers. That is a true team and they greatly added to my recovery. I will be forever grateful for my team and am glad I am part of Evercare Hospice.

Gail Bekebrede, RN Case Manager

I have been a nurse for almost 37 years, spending all of that time in long-term care facilities. That is, up until last August. I was working in a skilled nursing facility where a few of my residents were under the care of Evercare Hospice. I had dealt with many hospice services over the years. Most were good, some were not as good. But I was so impressed with the services that Evercare

provided and, more importantly, the manner in which they provided them, that I wanted to be a part of it.

For the first time in my long nursing career I am doing something different and loving every minute of it! Like the motto of the U.S. Army, it is the hardest job you will ever love. I know I was always doing something important, but this brings important to a whole new level for me. I feel this is care on a more personal level. I get so much satisfaction from doing the most simple of tasks because my clients and their families really appreciate the work that I do.

I have received many compliments from clients over the years and they have always made me feel good. But nothing tops the way I felt when one of my hospice clients told me, "I feel safe with you here." I am so glad I decided to try something new and I am also thankful Evercare Hospice gave me this opportunity.



Chauncya Lucas

Chauncya Lucas, Intake Coordinator

I moved to Phoenix and was searching for a job in health care that wouldn't just be a job. Never did I expect to find such a rewarding career. One of my most rewarding hospice experiences was when one of our patients was dying at the young age of 50. She was lonely because she was no longer able to get out the way she used to. She called the office

one day and I answered the phone and she said, "Chauncya, my nurse told me if I needed someone to talk to I should call you." We sat and just chatted for about 20 minutes or so, not about her illness, but just about everyday things like movies and food. She told lots of jokes! It was very rewarding for me to fill her need of having someone to talk with. I feel that's what makes a good hospice: A compassionate and caring team.

Anne Chida, Hospice Chaplain

My first experience with hospice happened when I worked in home health care in the early 1980s. The first family I worked with had me "hooked." It was fall, and our patient was a man dying of lung cancer. He was part of a very loving, close family that was financially very poor but rich in other ways. The one thing he wanted me to do for him was to plant tulip bulbs along his walkway. His wife of more than 50 years loved tulips, and he wanted her to know when she saw those tulips come up that he loved her even though by that time he would likely be gone. I shed a few tears while I was planting those bulbs.

I was, and continue to be, awed by the meaning of love that I found in so many "little moments" with our hospice families. I stayed working as a social worker in hospice off and on since that first experience. When I hit middle age I decided to return to seminary and become a minister so that I could work as a hospice chaplain. I love being a hospice chaplain and feel that I get far more out of my job than I could ever give. What other job teaches you about love? And that, in the end, loving one another is all that matters. I am given the gift of walking beside people in some of the toughest and most beautiful moments life holds. Each family leaves me richer in their wisdom and increases my gratitude for my own life and loved ones.

Dr. Rhonda Randall, Physician

What makes a good hospice? One sentence: The expertise, commitment, compassion and availability of the staff to the patient and their caregivers. ❁

For the first time in my long nursing career I am doing something different and loving every minute of it.



FIVE WISHES:

PROTECTING YOUR DIGNITY AT THE END-OF-LIFE

dURING A MEDICAL CRISIS, families and friends are often asked a series of painful and difficult questions: What types of medical interventions would your loved one want? What will make them most peaceful? Who do they want to be surrounded by, when and how?

Five Wishes® is an innovative document that has dramatically changed how people are tackling these important end-of-life topics, opening a dialogue among family members, friends and doctors and helping people voice their preferences and expectations. It is unique because Five Wishes looks to all of a person's needs — medical, personal, emotional, social and spiritual — and addresses them in simple, straightforward language, without clinical terms or legal jargon.

“One of the biggest misconceptions people have is that their spouses or children will know what they would want if they can't speak for themselves,” says Paul Malley, president of Aging with Dignity, a nonprofit organization that publishes Five Wishes. “Once people start having the conversation, they realize that their loved ones actually have very different expectations from what they would have anticipated. Five Wishes creates a forum to have that discussion before a crisis hits.”

Five Wishes addresses the things that can matter most at the end-of-life, such as being comfortable, staying in familiar surroundings, having loved ones nearby and receiving religious support and counsel. “That's why Five Wishes has been called the ‘living will with a heart and soul,’” explains Malley. “It provides a format for you to speak openly and honestly about all the elements of care and community that are important to you as an individual.”

Specifically, Five Wishes helps you explain to family, friends and doctors:

1. Which person you want to make health care decisions for you if you can't make them yourself.
2. The kind of medical treatment you want or don't want.
3. How comfortable you want to be.
4. How you want people to treat you.
5. What you want your loved ones to know.

Five Wishes was written with the help of the American Bar Association's Commission on the Legal Problems of the Elderly and has been deemed a valid, stand-alone living will by 42 states. It is available in 23 different languages, plus American English Braille. It's also very easy to use. All you have to do is check a box, circle a direction, or write a few sentences to communicate what you want (or don't want) at the end-of-life.

A pediatric version of Five Wishes, called “My Wishes,” has been created to guide conversations among seriously ill children, their parents and health care providers and provides space for children to convey their wishes through words or drawings.

While Five Wishes is often used with patients who are facing a terminal diagnosis, it is equally valuable for those without any current medical concerns. “Life is unpredictable and an accident or unexpected health event can happen at any time,” says Malley. “Five Wishes is about being prepared, so that no matter when these issues come up, you can take comfort in knowing that your wishes will be clearly communicated and respected, with a written record that preserves your rights and your dignity.”

Five Wishes creates a written record that helps preserve your rights and your dignity.

* Five Wishes Q&A

Why should I fill out Five Wishes?

Without an advance directive like Five Wishes, you may have no control over important medical care decisions that will be made if you ever get seriously ill, such as whether to give you life-support treatment or aggressively treat your pain. Completing Five Wishes is a gift to your loved ones as well, so they are not left to guess what you would have wanted.

What makes Five Wishes different?

Five Wishes is the only advance directive/living will that speaks to all of a person's concerns, not just the medical and legal ones. Matters of comfort, dignity, pain management, personal and spiritual issues, family reconciliation and memorial matters are all addressed. It meets the legal requirements

and has been called the closest thing available to a national advance directive.

Does filling out Five Wishes guarantee that my wishes will be followed?

Your doctor is required to follow your wishes according to the laws of your state. Discuss your wishes with your doctor after providing a copy of your Five Wishes for the medical record. It's also wise to pick a health care agent to advocate for you and your wishes.

Will my Five Wishes be honored wherever I go?

When you travel, bring a copy of your Five Wishes in case you become seriously ill. Federal and most state laws are designed to honor your wishes, no matter how you express them.

* How to be a good health care agent

A health care agent is the person designated to make care decisions when another person is unable to communicate on their own. Aging with Dignity offers this advice to health care agents:

- » Know your loved one's wishes ahead of time. Ask detailed questions and be sure you understand what he or she would want. If you feel you cannot follow their wishes to act on their behalf, ask that someone else be chosen.
- » Tell doctors, nurses and other caregivers that you are the health care agent and how to

contact you. Give them copies of the signed Five Wishes document.

- » Ask questions of the doctors and nurses and follow up to be certain they are following your instructions. Be courteous but firm.
- » If you encounter problems, speak with a social worker, patient representative or chaplain. If a doctor doesn't want to follow your loved one's wishes, contact the ethics committee of the hospital, nursing home or hospice.

i Five Wishes can be ordered online at www.agingwithdignity.org/5wishes.html or by calling 1-888-5WISHES (1-888-594-7437). To preview the full Five Wishes document, visit www.agingwithdignity.org/5wishes.pdf.

about evercare hospice



James

FULFILLING DREAMS:

COMFORT, CLOSURE AND CELEBRATION

DREAM FOUNDATION IS THE first and largest national wish granting organization for people age 18 and older who suffer from life-limiting illness. Their mission is to enhance the quality of life for patients and their families, helping adults realize a final dream.

Dream Foundation has granted thousands of dreams to adults who are emotionally, financially and physically devastated by terminal illness. They work with volunteers, hospices and healthcare organizations nationwide to identify prospective recipients. All dream recipients have been diagnosed with a terminal illness and have a life expectancy of one year or less.

"We believe that adults at the end-of-life should receive managed physical care and comfort, and that every adult deserves the peace of mind that comes from knowing he or she has achieved a final wish, a goal or a dream," says Dream Foundation Founder and President Thomas Rollerson. "The emotional care Dream Foundation is able to provide is a natural accompaniment to end-of-life care provided by hospices. Working together, we are able to ease the passage and provide peace and resolution."

A dream can be as simple as seeing a dear friend one last time, keeping a promise to young children for a special family trip, or providing resources that help support a patient's independence. "Our goal is to ensure that no adult whose life will end prematurely due to a terminal illness should ever pass from this earth without realizing one final wish from the heart," says Rollerson. "We cannot provide a cure for dreamers, but we can dramatically impact the quality of their fragile lives with the

joy experienced from a dream come true."

Dream Foundation has been designated as one of the recipient organizations of donations received by Evercare Hospice & Palliative Care, and several Evercare patients have been granted their wishes. "Hospice is a heart-driven component of health care, where compassion, respect and dignity are paramount in serving a patient's needs," says Patricia Ford, vice president of Evercare Hospice and Palliative Care. "It's important to support the individual wishes of patients and help them create the closure they need."

Some wishes funded by Evercare Hospice donations include: a GED study guide, tutor and application fees; a home wheelchair ramp, gift cards, sports memorabilia and a laptop computer. Here are the stories of three more patients who had personal wishes fulfilled through the Dream Foundation.

James: Faithful NFL Fan

James has been diagnosed with lung cancer that has spread to various parts of his body. Now in hospice care with Evercare in Concord, California, he was given a prognosis of less than 3 months. In the time that remained, his dream was to take his youngest brother, George, to a San Francisco 49ers game. A faithful fan of the 49ers for many years, James had never attended a game in person.

With the help of his hospice care worker and Dream Foundation, James saw his dream realized. On Nov. 12, James attended his first professional football game and the experience was beyond expectations. The 49ers staff generously arranged for special parking, field access during warm ups and a meet and greet with ex-49er Steve Bono. James and his brother were also provided accommodations

at the SFO Marriott, courtesy of the 49ers. It was a memorable trip for James who later wrote, "I cannot put into words how much this means to me. Thank you from the bottom of my heart for this wish come true."

Katherine: Independence at Home

Katherine, who lives alone, has been diagnosed with ovarian cancer. She receives hospice care through Evercare in Norcross, Georgia. At the time her hospice care social worker contacted Dream Foundation, Katherine was living on the main floor of her two-story home because her staircase lacked a proper handrail. Her dream was to have a banister installed that would enable her to safely use the stairs. The Dream Foundation granted Katherine her dream, working with a local contracting company to have a handrail installed. She is grateful to now have restored access to the second floor and full use of her home.



Katherine



Lillian

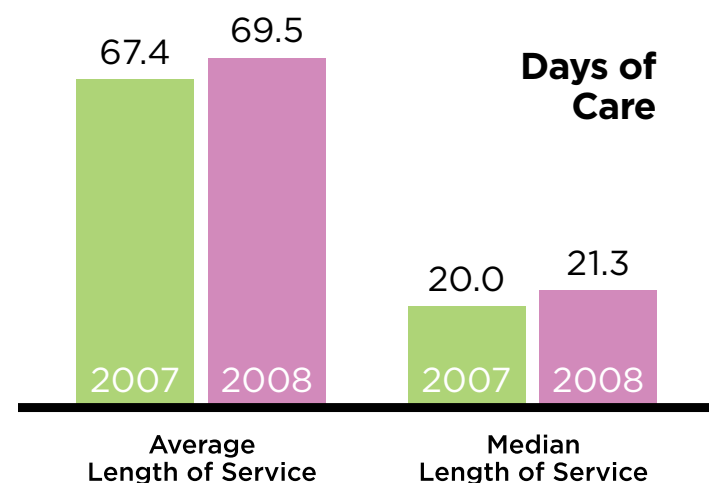
Lillian: Opening Doors

Lillian has been diagnosed with chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF). In hospice care with Evercare in Waltham, Massachusetts, Lillian must receive oxygen 24 hours a day and is bed-bound most of the time. Lymphedema in her right leg has made it even more difficult for Lillian to walk and she has seldom been able to venture outside with her children and grandchildren. Because of her condition, Lillian dreamed of acquiring a power chair that would enable her to move around more freely and enjoy quality time with her family. This December, Lillian's dream came true when Dream Foundation and the Scooter Store presented her with a new power chair. She is grateful for her newfound freedom and overjoyed with every new opportunity to spend time with her family. 🌟

Working together, we are able to ease the passage and provide peace and resolution.

Request a Dream Foundation Wish

If you'd like to request a wish on behalf of a patient, visit www.dreamfoundation.org/dream-request.html and follow the instructions for hospice professionals near the bottom of the page. Wishes must be submitted by hospice professionals only and cannot come from the friends or family members of patients.



of factors including disease course, timing of referral and access to care. The median length of service in 2008 was 21.3 days, an increase from 20.0 in 2007. This means that half of hospice patients received care for less than three weeks and half received care for more than three weeks. The average length of service increased to 69.5 days (from 67.4 in 2007).

CAN HOSPICE EXTEND A PATIENT'S LIFE?

Hospice care may prolong the lives of some terminally ill patients. In a 2007 study², researchers selected 4,493 terminally ill patients with either congestive heart failure or cancer of the breast, colon, lung, pancreas, or prostate. Patients who chose hospice care lived an average of one month longer than similar patients who did not choose hospice care.

WHAT'S THE MOST COMMON DIAGNOSIS AMONG HOSPICE PATIENTS?

When hospice care in the United States was established in the 1970s, cancer patients made up the largest percentage of hospice admissions. Today, cancer diagnoses account for fewer than half of all hospice admissions (38.3%). The top four non-cancer primary diagnoses for patients admitted to hospice in 2008 were debility unspecified (15.3 percent), heart disease (11.7 percent), dementia (11.1 percent) and lung disease (7.9 percent).

¹Facts and Figures: Hospice Care in America. National Hospice and Palliative Care Organization, November 2009.

²Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window. Journal of Pain and Symptom Management, Vol. 33 No. 3 March 2007.

³Palliative Care and Oncology: Growing Better Together. Journal of Clinical Oncology, Vol. 27 No. 2, January 10, 2009.

HOW MANY HOSPICES ARE OPERATING TODAY?

The number of hospice programs nationwide continues to increase — from the first program that opened in 1974 to approximately 4,850 programs today.

DOES HOSPICE SAVE MONEY?

Findings of a major study demonstrated that hospice services save money for Medicare and bring quality care to patients with life-limiting illness. Researchers at Duke University found that hospice reduced Medicare costs by an average of \$2,309 per hospice patient. Additionally, the study determined that Medicare costs would be reduced for seven out of 10 hospice recipients if hospice had been used for a longer period of time.

THE BOTTOM LINE

There's no doubt that hospice care is steadily improving the end-of-life experience for millions of people. While it's tempting to add up all the numbers and reports, the statistics and the stories, the state of hospice in America will ultimately be measured individually, uniquely and personally by each family and each patient it touches.

"As valuable as our specialized training, knowledge, skills, and experience all are, we ultimately become specialized one patient and family at a time," writes Ira Byock, M.D.³ "At the end of the day, it is not our segmented programs and specialties that matter, but the special expertise we bring to the collaborative process of patient and family care." ❖

RESOURCES

VISIT THESE WEBSITES FOR COMMUNITY SUPPORT AND VALUABLE INFORMATION ABOUT HOSPICE, PALLIATIVE AND LONG-TERM CARE.

» **EVERCARE™ HOSPICE & PALLIATIVE CARE** (www.evercarehospice.com or 1-877-765-3917) offers education, resources and services for patients and families through its interactive website and 24-hour phone line.

» **CARING CONNECTIONS** (www.caringinfo.org or 1-800-658-8898) is a program of the National Hospice and Palliative Care Organization, providing extensive resources and support for patients and families who are coping with end-of-life issues.

» The **NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION** (www.nhpco.org) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. It offers education and information for practitioners, patients and families.

Through the NHPCO website, you can search for a hospice or palliative care program in your community. Use the "Find a Provider" search page at www.iweb.nhpco.org/iweb/Membership/MemberDirectorySearch.aspx.

» **MEDICARE** covers most hospice services for eligible beneficiaries. You can view a special publication online for more information about Medicare hospice benefits at <http://evercarehealthplans.com/pdf/MedicareHospice02154.pdf>.

» **AGING WITH DIGNITY** (www.agingwithdignity.org) provides practical information, advice and legal tools on end-of-life and long-term care issues, including the Five Wishes planning document (www.agingwithdignity.org/5wishes.html).

» **CARINGBRIDGE** (www.caringbridge.org/evercare) helps you stay connected with friends and family during an illness through a free, personalized website.

» **LOTSA HELPING HANDS** (www.caregiver.lotsahelpinghands.com) is a private, web-based tool that allows you to share your needs and let family, friends, neighbors and colleagues assist with daily caregiving tasks.

» The **WELL SPOUSE ASSOCIATION** (www.wellspouse.org) focuses on the needs of all spouses caring for a chronically ill or disabled husband, wife or partner.

» **CENTER FOR PRACTICAL BIOETHICS** (www.practicalbioethics.org) provides tools and resources about end-of-life decision making, including the Caring Conversations Series.

Cancer diagnosis now accounts for fewer than half of all hospice admissions. The top four non-cancer primary diagnoses for hospice in 2008 were unspecified debility, heart disease, dementia and lung disease.